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13. Abstract ***(Maximum 200 Words)*** *(abstract should contain no proprietary or confidential information)*

The purpose of the current study is to elaborate the beliefs and culturally embedded meanings that a population of low income, uninsured African American women held toward breast cancer and breast cancer screening. During Year 02, we conducted technical analyses of completed Phase 1 interviews that were obtained from African American women who were eligible to receive, but who chose to decline, free screening mammograms. Results obtained to date suggest that screening mammograms are physically and emotionally difficult experiences for the women, not neutral procedures for detecting early disease. Women equate mammograms with disease, not with merely early detection. For some, mammograms cause disease and put them at higher risk because of radiation exposure. Early diagnosis and treatment for many do not equate with cure, but with inevitable disease progression. Risk factors for breast cancer were not well understood and some women generated a unique set of risk factors that have no prior evidence in research literature, e.g., having large breasts. Having breast cancer means losses, deformity, remaining single, altered sexual behavior with a partner, and burdening one's family. There is little evidence of hope for cure in the interview data nor for surviving the diagnosis of breast cancer, even when detected early. Results to date have substantial implication for developing new outreach and educational messages.

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Introduction

Breast cancer screening programs hold the greatest promise for early detection of the disease. However, rates of participation in breast cancer screening programs, particularly in community-based samples, has been extremely disappointing for low income, uninsured African American women. The purpose of this research grant is to describe and elaborate the perceptions, beliefs, and culturally embedded meanings that a population of low income, uninsured African American women hold toward breast cancer and breast cancer screening. There are two phases to the study: Phase I involves case intensive interviews and Phase 2 involves focus groups. Both phases involve a population-based sample of low income, uninsured African American women who were eligible for but declined to receive a free screening mammogram. Year 02 activities relate to only Phase I of the study; accomplishments in Year 02 are described next.

Body of Report

In 2002, an estimated 257, 800 women in the U.S. will be newly diagnosed with breast cancer (ACS, 2002). Although there is high potential for cure with early disease, detection of early, compared to late stage disease, is dependent on successful screening and early detection methods. When the disease is confined to the breast, 10-year survival rates range from 65-80%. When diagnosed at Stage 3 or 4, the 5-year survival rates are only 2 to 5%. Between 1993 and 1995 [the most current data available], 48.1% of the new cases in African American women in Seattle-King County, the largest recruitment county for this study, were diagnosed at late stages compared to 32.4% in Whites (Washington State Cancer Registry Data, 1999).

Early hopes were held for increasing participation in breast cancer screening programs for low income, African American women when Congress passed the Breast

and Cervical Cancer Mortality Prevention Act of 1990. This act authorized the Centers for Disease (CDC) to establish a national program called the National Breast and Cervical Cancer Early Detection program (CDC, 1998). By guaranteeing access, the assumption was that stage at diagnosis would be similar for all populations of women (Zaloznik, 1995).

Although this national screening program has resulted in increased participation rates compared to pre-program levels, success rates have been less than ideal. In Washington state, indigenous outreach workers have been trained to outreach African American women eligible for BCHP free mammography screening services as part of the CDC- and locally funded screening initiatives. However, finding these women through outreach workers and then successfully enrolling them into the BCHP-sponsored program has been a particular challenge and onerous task. As the director of the program in the largest recruitment county reported recently, "Finding these women [and outeaching them successfully] is like finding a 'needle in a haystack' " (Phillips-Angeles, July, 2002, Personal communication).

Evidence beyond the state of Washington is that African American women are more likely to be diagnosed with advanced (Stage III or IV) disease at initial time of diagnosis than are Caucasian women (Jones, Kasl, Curnen, & others, 1995; Lannin, Mathews, Mitchell, & others, 1998). This is prognostically very unfortunate news. In a recent population-based study in Connecticut, African American women were diagnosed more commonly with later stage disease (age-adjusted odds ratio [OR]-2.01, 95% confidence interval) than were white women (Jones, Kasl, Curnen, & others, 1995). In a recent case-control study of African-American women, being African American significantly predicted diagnosis of advanced stage (odds ratio: 3.0, 95%

confidence interval), as did having low income (OR, 3.7, CI 95%),as did being uninsured (OR 2.5; 95% CI) (Lannin, Mathews, Swanson, Swanson, & Edwards, 1998).

Even when breast cancer screening programs are made available, accessible, and offered free of charge, African American women compared to White women do not always participate in them (Zaloznik, 1995; McCarrhy, Yood, MacWilliam, & Lee, 1996). See reports by Abbott & others, 1999; Adderley & Green, 1997; Bernstein, Mutschler, & Bernstein, 2000; Bowen & others, 1997; Burnett & others,1995; Champion & Menon, 1997; Danigelis & others, 1995; Davis, 1998; Erwin & others, 1999; Lawson, 1998; McDonald & others, 1999; Miller & Champion, 1997; Phillips & others, 1999; Stoddard & others, 1998.

What is known with greatest confidence are those factors that predict utilization in women who participate in screening programs or who are diagnosed with breast cancer. See critical reviews by Hoffman-Goetz & Mills, 1997; Lowe & others, 1995. Although knowledge of these factors is important, it tells us nothing about women who do choose to ***NOT*** participate in breast cancer screening programs. As a result, neither scientists nor clinicians can assume that factors affecting utilization in women who obtain screening are the same factors that affect women who choose to not be screened. This dearth of data based information means that program planners, health educators, and health service providers have limited information on which to tailor the messages in culturally appropriate terms (Mahloch, Thompson, & Taylor, 1998). Information from these eligible but non-participating women is essential for designing culturally sensitive and informed materials, outreach, media and channel messages (See Adderley-Kelly & Green, 1997; Ansell & Others, 1994; Brown & Williams, 1994; Crane & others, 1998; Eng, 1993; Erwin & Others, 1999; Kaluzny & Others, 1994; Mahloch & Others, 1998; Reynolds & Others, 1990; Rimer, 1994).

The current study assumes that ***cultural and psychosocial variables***, yet to be fully described in the research literature, affect participation rates in breast cancer screening programs for financially challenged and uninsured African American women. The long-range goal of this study, beyond the funding period, is to develop culturally informed outreach messages, printed materials, and program messages that are responsive to the culturally embedded meanings and perceptions of fiscally challenged, uninsured African American women.

Statement of Work

See Figure 1 for the study's original objectives. See Figure 2 for the Statement of Work.

Figure 1: Overall Objectives of Study, Including Phase I and II

1. To conduct and audio-tape record case intensive interviews with African American uninsured women of poverty who are drawn from a population data base of eligible women who were referred into but did not enroll in the breast cancer screening program in the Breast and Cervical Health Program in Washington state. [Phase 1 activities.]

2. To use technical methods to inductively code and content analyze the transcribed audio-tapes from the interviews in order to identify factors associated with non-attendance in free breast cancer screening programs. [Phase 1 and 2 activities.]

3. To conduct four focus groups involving African American women from the same population of uninsured fiscally challenged women in order to check the accuracy and thoroughness of the factors associated with non-participation that were identified from the coded interview data. [Phase 2 activities.]

Figure 2: Statement of Work for Year 02

1. Refine phone records and contact methods in order to minimize "loss to follow up" of potentially eligible women for Year 02 interviews from population data base.
2. Recruit eligible women into the study for Phase 1 interviews.
3. Code completed interviews using scientific methods for inductive coding.
4. Conduct quarterly meetings of the Community Advisory Committee as a means of structurally linking with community partners who are "stakeholders" for the study results, outreach, and screening services for fiscally challenged African American women.

Items on this Statement of Work are described next for Year 02 activities.

STATEMENT OF WORK

1. Refine phone records and contact methods in order to minimize "loss to follow up" of potentially eligible women for Year 02 interviews from population data base.

STATUS: Accomplished.

The greatest "loss" of eligible women to the study in Year 01 was through "bad phone numbers." As a result, in Year 02, we instituted a new method for cross checking the accuracy of the phone numbers on record in the population data base before attempting contact with the potential study participant by the intermediary.

Dr. Lin Song, Ph.D., epidemiologist for the Breast and Cervical Health Program, cross-checked the women's phone number of record in the population data base with the woman's phone number noted on other documents. These cross checks yielded a revised list of phone numbers.

STATEMENT OF WORK

2. Recruit eligible women into the study for Phase 1 interviews.

STATUS: Recruitment calls were made to the total list of potentially eligible African American women.

The total population of potentially eligible women available to the study for Year 02 was 222. This total involved two separate lists that were obtained from the epidemiologist in a confidential data file that was downloaded to the intermediary. The first list consisted of 162 women and the second list consisted of 60 women. Recruitment efforts for each list were tracked separately and are reported next. Detailed spreadsheets were maintained on all recruitment activities by the intermediary. in order to track the frequency, timing, and dates of phone contact attempts by the study intermediary.

On the list involving 162 women, 95 women (95/162= 59 %) were immediately ruled out by the intermediary because, despite best efforts, phone numbers were "bad" phone numbers. "Bad" numbers included phone numbers that were no longer in service; numbers that were incorrect, i.e, linked with someone other than the woman; or the intermediary was explicitly told by the person answering the phone that the woman was no longer there. The remaining 67 (67/162= 41%) women were women whom the intermediary sought to contact.

Each woman on the contact list received a minimum of three phone contact attempts in Year 02. More specifically, 132 of the women were called 3 times; 30 women were called between 4 to 6 times. [The intermediary made 4 or more phone contact attempts for the 30 women under the direction of Lewis; we were trying to see if a larger number of contact attempts would increase the intermediary's likelihood of successfully

contacting the study participant. Based on prior research by Shapiro, greater phone contacts might could potentially yield higher success in contacting the woman. After monitoring, however, a higher volume of contact attempts in our study was not more successful. We then implemented 3 phone contact attempts for the remainder of the women.]

Of the 67 women whose phone number was functional, 19 (19/67= 28 %) women claimed they had obtained screening mammograms elsewhere. Another 5 women claimed they did not recall being outreached by a BCHP worker. Another 4 women had died, according to the person answering the phone. Another 15 women never answered the phone and only message machines turned on, despite 3 or more attempts at contact. Of the 67 women, 4 women said they *wanted a free screening mammogram* and were referred to the BCHP program staff. Another 7 women had phone numbers that were constantly busy, no matter what day or time of day the intermediary attempted to contact them. Finally, 13 women (13/162= 8 %) explicitly refused to participate in the interview study. [This refusal rate contrasts with a refusal rate of 15 % that we reported in our Year 01 Annual Report.]

The second list of potentially eligible women involved another 60 women. These women were women newly enrolled in BCHP or newly outreached for BCHP by indigenous phone workers. The pattern of phone recruitment for these potential study participants was similar to the pattern for the 162 women previously described. A total of 17 (17/69= 28 %) had "bad" phone numbers. Another 16 (16/60= 27%) had answering machines and were never successfully reached by the intermediary, despite multiple attempts. Another 13 women (13/60= 22 %) had phones that rang and rang or were busy but were never answered by either a person nor an answering machine. Seven women (7/60= 12%) claimed they received screening mammogram elsewhere.

Two women said they were never outreached by the BCHP worker and 1 women died, according to the person answering the phone. Two of the women who were contacted said they wanted to obtain a free screening mammogram and were referred to BCHP program staff. Finally, only 3 women (3/60= 5%) explicitly refused to participate in the interview.

Note that most women, in Year 02, were lost to follow up because of "bad" phone numbers. This occurred despite our team's heightened efforts to cross-check the accuracy of the phone numbers. Note, too, another 49% were "lost" because, despite best contact efforts, no person actually picked up the receiver to answer the intermediary's phone contact attempts. (We speculate that this latter group includes persons who use their answering machine to screen out unknown callers.) In Year 03, we plan to engage intermediaries at the clinic site, along with the state epidemiologist, in cross-checking the phone numbers in the population data base.

In addition, two of the most frequently cited reasons for ineligibility, once the woman was successfully contacted by the intermediary, was the woman's claim that she had ***not*** refused a free mammogram or that she had obtained a mammogram elsewhere. That is, when successfully reached, women claimed they did NOT remember being outreached for a free mammogram or they claimed they NEVER refused a free mammogram or they claimed they obtained a screening mammogram elsewhere. These responses are similar to those that we obtained during our Year 01 activities. This high rate of ineligibility, despite the woman's name being entered into the population data base as eligible, raises four hypotheses: 1) some women may have recall bias; 2) some women may have a self-enhancement bias [they want the intermediary to view them in positive ways, including trying to 'save face' by claiming they were not outreached]; 3) outreach workers may be inaccurately reporting outreach

activities; or 4) outreach workers' methods and messages to outreach the women are not specific nor strong enough to cross a threshold of awareness. [Note: Only African American women who were logged into the data base from either the clinics or the outreach workers' logs were available to this study team's population data base. That means that, at minimum, either the outreach worker obtained the name of the woman through direct contact with her in offering the free screening mammogram or the woman was actually seen at a provider clinic for an annual exam, during which she chose to NOT obtain a screening mammogram.] We are unable, at this time, to precisely determine which type of error is occurring in the population data base. We do think that future scientists need to be aware of this pattern of responses; our poster for the Era of Hope Conference, September, 2002, will discuss these methodological issues. In addition, the percent of non-working phone numbers in a population data base has substantial negative consequences for future studies which rely on such data bases for recruiting study participants. This, too, will be part of our presentation at the Era of Hope Conference, September, 2002.

STATEMENT OF WORK

3. Code completed interviews using scientific methods for inductive coding.

STATUS: Accomplished.

The main new results for Year 02 involve a summary of the coded interviews that have been analyzed to date. Most of these results are **unknown** in prior published literature. All results have substantial importance for the development of new outreach and educational materials for fiscally challenged African American women like those interviewed in the current study. To our knowledge, these are the first set of results obtained from women who chose to not obtain a free screening mammogram.

Both Lewis and Phillips-Angeles coded the interview data. In addition, Lewis (Principal Investigator) conducted three separate workshops in order to train the community partners and stakeholders on the methods to technically code the completed interviews. The goal was to have them gain technical coding skills as well as full ownership of the results and implications for program development. Program ownership is known, from prior research, to result in program changes and refinements, in contrast to only passive awareness of the data.

Lewis monitored and quality managed every step of their coding processes. See Appendix A and B for examples of coding that were generated as part of this activity. A summary of the data analytic methods follows. These workshops were essential, given that this is a community partnership grant. Phillips-Angeles (Co-PI) participated in the workshop and invited community partners/stakeholders to be trained.

A multi-phased process was used to analyze the transcribed interview data based on the content analytic methods described by Krippendorf (1980), Spradley (1979, 1980), Strauss and Corbin (1990), Glaser and Strauss (1967), and Strauss (1987). Data were initially unitized: the units of analysis in the transcribed data were identified and verified by two coders. The unit of analysis that was coded was the complete idea, not the complete sentence. A complete idea was defined as a verbal expression that included both an explicit or implicit verb or noun. As a result, compound sentences were analyzed into their component parts and coded as multiple units.

After unitizing the data, open coding occurred. Open coding involved analyzing, comparing, and categorizing data (Strauss & Corbin, 1990). Each unit of analysis was reviewed and organized into categories of units based on a common element. This first level of categories involved open coding and was based on the manifest, not latent, meaning of the words (Krippendorf, 1980). See Appendices for examples of verbatim

(emic) categories and related quotes from study participants; each question on the interview was coded separately. In Year 03, results across categories and across questions will be analyzed in order to identify an explanatory theory that predicts under what conditions, and why, study participants chose to not obtain a free screening mammogram.

Whenever possible, categories were labeled with emic, not etic, labels (Lewis, Haberman, & Wallhagen, 1986). Emic labels are labels in the words of the participants, not the coder. Emic categories are synonymous with "in vivo" codes or codes based on the words of the study participants (Strauss, 1987). Constant comparative analysis occurred concurrent to the identification of the categories and involved three comparisons (Haberman & Lewis, 1990). This analysis meant that each unit of coded data was compared with each category in order to maximize the fit of the unit with the category. Units of analysis were also compared with each other within each category in order to maximize the consistency of the grouped units. Finally, all categories and units of analysis were compared with the other categories and units in order to maximize their unique and non-overlapping quality.

We report results-to-date from the Phase 1 interviews. Coding is ongoing and will continue through Year 03. We also anticipate that additional interviews, to be completed in Year 03, will potentially modify the results. For ease of understanding, results across four questions that have been coded are summarized below as a discursive report. We envision the development of at least one professional paper in Year 03 based on these study results.

Summary of Themes Derived from Coded Results Analyzed to Date

Breast cancer, mammograms, and treatment for breast cancer are equated with negative terms and negative consequences for many of the study participants. Although

early detection through mammography is the medical community's most efficient way to downstage and diagnose breast cancer, these terms were often negative and valence-laden for the interviewed women. Furthermore, these terms were often understood as isolated ideas, not as an interrelated set of terms that relate to early disease detection in order to save the lives of the women.

Risk factors were not well understood by study participants. None of the medically known risk factors were contained in the interview data obtained to date. Some women had instead generated a list of unique risk factors, including large breast size or smoking or drinking habits. None of these unique risk factors have a medically based rationale.

Mammograms were not neutral procedures to the study participants. They were instead physically and emotionally painful and exposing experiences for the women. Finally, there were horrific consequences of being diagnosed with breast cancer for many of the women. Further description of these results follow.

Breast Cancer and Treatment

Breast cancer was equated with death, suffering, pain and the loss of a breast in the study data. Although there were isolated exceptions in the interview data, it was as if the "clock" were turned back to the 1940s and 1950s for study participants: breast cancer equaled sad or bad things. With rare exception, success by early detection and treatment was not a part of the women's framework of understanding mammography. As one woman stated, "It (the cancer) will take my life and take me from my family." [Code 17976, Line 146]. Another offered, " I mean when I think of cancer, I think of people dying. I've lost so many relatives, so many, you know." [Code 111116, Lines 108-111].

The link between breast cancer, disease progression and death was accentuated by the women's personal experiences with friends and family members who had a diagnosis of cancer and got worse after diagnosis, not better. Never once did any participant reason that things got worse because a woman waited too long before being diagnosed. Instead, cancer was cancer and disease staging was often not a part of the women's frameworks. As one woman stated, "And so, when I hear 'cancer,' I'm kind of afraid of that word due to the fact that there's no cure for cancer." [Code 15556, Line 89-92].

Study participants recalled examples of very young women they knew who died of breast cancer. Commonly, family members were also remembered who died from the cancer, including breast cancer. The logic in the study participant's thinking was that cancer resulted in death. Discovering the "lump" led to death, even when a woman went to a physician after discovering the lump.

There was little evidence that women knew the difference between the diagnosis of early versus late stage breast cancer. Instead of thinking of mammograms as the best known method to detect breast cancer, women instead linked the detection of the breast lesion through mammography with poor outcomes. With few exceptions, women recalled that detection of the lump, even with medical intervention, resulted in poor outcomes, not down-staged disease and survival.

A very few women reported that breast cancer could be diagnosed early; that also meant, for them, that the outcomes could be better. "I used to think of breast cancer as a killer. Now I think of it as a situation...if people catch it in time, it's no longer a killer....I think we just need to take control and say I have it. I'm going to deal with it. And I'm going to do the best I can do and I'm going to live until I die." [Code 149888, Lines 49-51; 71-74]. Some women thought that removing the breast saves a

woman's life. As they stated, "if your breast get off (sic), you still have your life." [Code 28; Lines 86-87].

But commonly women viewed breast cancer as an incurable disease. As one woman stated, "I think of it as an incurable disease." [Code 125, Line 30]. Another offered, "Cancer just eats your body up; just devastating." [Code 4, Line 14]. Another woman, in a separate interview, echoed her words, "So, like, their insides of their bodies are being eaten up by it (cancer)...I think of your body being eaten away." [Code 48, Lines 14 and 44]. Note the link between breast cancer and dying, not surviving in the following woman's interview data. "If it's malignant, I'll be thinking about dying. If it's benign, I would be thinking about surviving." [Code 16553, Line 220]. Another woman stated, "I would be afraid, of course, because I know there's no cure for cancer, really, even if you catch it in time. There isn't a guaranteed cure." [Code 19293, Lines 161-164].

Pain and fear of pain were dominant concerns for the women with breast cancer. As one woman stated when asked about breast cancer, "Your cells are just going crazy inside your body and I can't imagine what that pain feels like." [Code 10943, Line 451].

Breast Cancer Means Many Losses

Breast cancer was equated with loss: loss of the breast and loss of relationships. Breast cancer also meant deformity. As one woman succinctly put it, "If a person has breast cancer, they've had to have either total mastectomees or they've gone in and they've just removed it [the cancer]. But they're always...they're always basically deformed..." [Code 10943, lines 52-54].

For many women, breast cancer meant losing a breast. For some, the loss of a breast was devastating. "I don't think I could live with myself if I lost my breasts...When I think of breast cancer, that's too close to my heart." [Code 15556, Lines 123-126].

For some women, their breasts were a critical component of their self-identity, including for large-breasted women. The following woman's statements capture the complex relationship between self-identity and breasts. "Losing a breast is just so detrimental to me. I'm so busy carrying around these suitcases [her breasts] for so long...I'd hate to put one suitcase down and keep carrying the other one. What I mean is that it's characteristic of a woman to have two natural breasts. And for me to lose one, you know. I'm so used to being fondled in certain ways, you know, by the opposite sex until...I would be embarrassed if I didn't have nothing there, you know. You only have one...one to feel on." [Code 1556, Lines 149-180]. Another woman elaborates the crisis of losing a breast. "Tell me they are going to cut my boob off. I would have a tissy, probably have a heart attack right there...Don't do this to me, don't take my breast, that scares me.... Knowing it's [the breast] gone and you can't replace it...We're going to have to take your breast. I just couldn't deal with it. Later they could come back and say we got to take the other one. Then I'd be breastless." [Code 111115, Lines 404; 407; 413; 417; 421]. Another woman summarized, "I think having a mastectomy and trying to deal with that would be worse than dying." [Code 111116, Line 954]. Note that the latter woman would rather die that lose a breast by mastectomy.

Some women linked breast surgery with the historical butchering or unnecessary surgeries of women by physicians who they called "butcher." As one woman said, "I'm reminded of how many women have had their breasts removed needlessly and unnecessarily. My aunt had her breast removed in the 60's or 70s when they didn't need to. She felt like half a woman. Removing a breast is like removing a man's scrotum. I think of breast cancer as something I never want to have happen to me." [Code 30764]. There was no evidence in the interview data that women knew about breast conserving surgery as treatment for early stage breast cancer.

Breast cancer was associated with changed or lost relationships both with members of the women's biological families as well as with future relationships with men. Here are a few examples from different study participants, all answering the question, "What is the worse thing you could imagine if you were to be diagnosed with breast cancer?" "To know that I would not be here to see my children grow up, my grandchildren...to know that I would pass before my parents would be devastating to me." [Code111113, Line 230]. "I wouldn't get to see my kids and my grandchildren." [Code 111114, Lines 301-302]. I wanted to help my kids grow up...my grandkids." [Code 18389, Line 674]. But the worst thing I would think about is my granddaughter I have. Who's going to take care of her?" [Code28, Lines 281-283].

Women feared that a mastectomy would mean that they would remain single. "If I had to get a mastectomy, that would mean that I would never get married." [Code 111116, Line 979].

Breast Surgery Puts You at Risk

Breast cancer involves, by medical definition, removal of the suspicious lesion. For some women, the surgery itself put the woman at increased risk for the cancer to spread or to get worse. "Sometimes I think when you have surgery for cancer, maybe the cancer just gets worse when it sees daylight." [Code 11114, Lines 39-43]. There were additional examples in the interview data in which the women thought the procedure itself caused the cancer to get worse. [This result is partly documented in prior research by others, but related to cervical cancer, not breast cancer.]

Mammograms as Painful and Exposing

Health care providers and health educators think of mammograms as helpful and efficient methods to detect breast cancer at early stage. That is not the dominant view of the procedure by the current study participants. For study participants, mammograms

were both physically difficult and interpersonally distressing examinations that left them feeling pain and distress long after the mammogram appointment. Pain for the women was both physical and personal.

Physical pain came from the procedure itself. They described the pain as "pinching," "mashing," "squeezing like a pancake," and "smashed." One woman likened the pain to the pain associated with having a baby. "Psychologically I'm almost like this, give me a valium or give me a shot or something before I go in there because I'm getting very frightened of that pain. It's like you're having a baby, you know, it hurts to have a baby...if you can just put it off, I'll wait another few years before I'm gonna have another baby [that is, have another mammogram] because I know the pain's coming." [Code 93, Lines 504-509].

Some women claimed they were so tender afterwards that they could not have sex or even brush up against their own breasts because of the tenderness. Women reported, too, that they developed bruises from the mammogram.

One woman said having a mammogram was like having your finger shut in a car door. "...the machine's gotta do something; the machine does not know the pain it's inflicting. It's just trying to get this asymmetric breast to contour like a pancake and it's just not happening. But it manages to flatten it out with such pain. It's like closing your finger in a car door, how long do you want to keep your finger in a car door. And you're gonna take your second finger and put it in another car door? You know what you just went through." [Code 93, Lines 443-445].

Mammograms were interpersonally difficult experiences for some of the study participants. The difficulty began, for some, when they detected a certain kind of negative "attitude" from staff at the screening facility. The women were distressed, too, by the response of the technician when the women disrobed for the procedure. Many

women reported that the technician gawked at the size or asymmetry of the woman's breasts. Some study participants also reported that they had personal difficulty in disrobing because they were embarrassed about the size of their own body.

Mammograms as Sources of Risk and Fear for Breast Cancer

Mammograms, although designed as an efficient method for screening for breast cancer, are for many women sources of risk and fear for the disease itself. Some believe that they are put at risk for breast cancer because of the radiation coming from the procedure. (This result about radiation has some prior documentation by others.] They reason that if the procedure was low risk, the technician would not step behind a lead shield while the woman herself –unprotected- is exposed. One woman put it this way. "So, I felt like maybe if anything was going to happen, I would get something from this mammogram as opposed to finding I don't have cancer. " [Code, 25862, Line 257]. Another woman said this, "Any time I go to x-rays I just feel antsy about it, the x-rays and radiation. I don't know how high the radiation is or anything but I've heard any stuff (radiation) isn't really good. Because, you know, you figure now, the person that's taking the pictures, they jump behind a lead shield." [Code 10943, Lines 369-380].

Mammograms are a source of fear for the women. This is a very rich finding in the data which we plan to further analyze. Their fear of mammograms comes from detecting the disease. This creates a double bind for the women; they are damned if they do not get screened and they are damned if they do get screened. They are damned if they **do not** get screened because the disease progresses to a level that is prognostically bad. There are damned if they **do** get screened because they they believe it either exposes them to radiation or the procedure itself is equated with finding the disease itself. Thus, since they fear breast cancer, they also fear the mammogram. This woman's words summarize this mammogram=fear of cancer dilemma "Is the

mammogram something that will or won't cause me to have some kind of operation or something, surgery or whatever." [Code 15868, Line 547)]. Note that she is not saying that the breast cancer causes her to have an operation; it is the mammogram that causes that. This is a key distinction!

Fear-driven models of health behavior are known to result in non-action. The analogue is to smoking cessation. Fear-driven models of smoking cessation have no history of success. This mammogram=fear of disease detection model must be targeted in new messages/program materials.

Risk Factors for Breast Cancer

There is substantial evidence that study participants do not understand risk factors for breast cancer. Study participants had personal understandings, not medically informed understandings, of the risk factors for breast cancer. Many had generated models of unique risk factors that they believed increased a woman's risk for developing breast cancer. There is no substantiation in the professional literature for any of their identified risk factors.

Interviews with participants have yielded the following risk factors: breast size [big breasts are associated with a higher risk for breast cancer]; smoking habits [smokers are at higher risk for breast cancer]; drinking habits [alcoholic drinkers are at higher risk for breast cancer]; being overweight [risk is particularly greater when the weight is in the stomach area]; and lifestyle, including what you eat [no specifics were given].

There was further confusion over risk factors when participants knew women who got breast cancer but had no history of smoking or drinking. Study participants were confused and wondered why such a woman with no known risk factor got breast cancer.

STATEMENT OF WORK

4. Conduct quarterly meetings of the Community Advisory Committee as a means of structurally linking with community partners who are "stakeholders" for the study results, outreach, and screening services for fiscally challenged African American women.

Year 02 activities included engaging community partners as members of the study team and conducting meetings of the Community Advisory Committee. These efforts were led by Ellen Phillips-Angeles, Co-PI. She organized the Community Advisory Group Meetings in Year 02 during which progress on the grant was fully described; issues in outreach and recruitment were dealt with; and preliminary results from coded interviews were discussed at length. See Appendix for example of a handout on open codes for one question that was discussed at the February, 2002 meeting of the Committee.

Members of the Community Advisory Board include physicians, nurses, health educators, and community members and agency staff within the public health, tertiary, and primary preventive service community. All members are long-time advocates of the health of African American women and include a breast cancer surgeon in Seattle (Dr. Patricia Dawson, M.D.) as well as the Director of Women and Children's Health for the State of Washington (Dr. Maxine Hayes, M.D., M.P.H.) Additional members of the Committee in Year 02 and on-going include Pama Joyner from the Washington State Department of Health, BCHP Program; Cobie Whitten, epidemiologist for Washington State in the BCHP Program; Karen Fennell, Tacoma-Pierce County Department of Public Health, BCHP Program; Cherie Minear, Puget Sound Susan G. Komen Breast Cancer Foundation; Rietta Williams, Community Health Care of King County; and Etta Williams, Senior Services, King County, among others.

Reportable Outcomes

A research abstract was developed and submitted for presentation to the Era of Hope, Orlando, Florida, September, 2002. See Appendix.

Key Research Accomplishments

1. A new method was implemented for cross-checking the accuracy of phone contact numbers in a population data base.
2. Four stakeholders/community partners were technically trained to conduct coding on transcribed interviews.
3. Transcribed interview data on a subset of the interview questions were technically coded by the investigative team (Lewis and Phillips-Angeles) and yielded detailed descriptions of the study participants' models of understanding of breast cancer, screening mammograms, risk factors for breast cancer, and the meaning of a diagnosis of breast cancer.

Conclusions

There is substantial evidence that many women have models of breast cancer and its causes that do not have a basis in research or professional practice. Their models often run counter to the medical profession's understanding of: what constitutes a risk factor; the rationale and benefits behind early detection through mammography; and treatment of early as opposed to late stage disease. Horrific negative experiences were reported with prior mammography reported. Women also reported that the diagnosis of breast cancer resulted in death, despite early diagnosis and treatment. Personal stories of women dying from cancer, including breast cancer, reinforced the women's negative views and fears about mammography. Screening mammography, rather than being viewed as a neutral, efficient method for early disease detection [and therefore positive outcomes] was instead viewed as putting the woman at risk and was itself equated with breast cancer itself. All results have substantial implication for the development of new and modification of existing outreach, educational, and breast cancer control messages and materials.

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Appendix: Example of Coding Worksheets for Mammograms

Discomfort/Painfulness/Pinching

[there's, um, discomfort to some, um, painfulness. And, um, that's about it.] #109, 169

[besides the discomfort at the moment] #10943, 371

[A lot of people scare themselves and scare each other by saying oh it hurts, it hurts so bad] #11, 168

[The only problem I have is the pinching them to death] #111115, 357

[It's pinching them because it pulling on them] #111115, 359

[That's the only problem I have because every time I had them done, I'd be so sore the next day, I can't even touch my breasts] #111115, 360

[So, that's the only problem I think, you know, having this ...having them pinching] #111115, 363

[That's the only problem I have, but that [*inaudible*] you know?] #111115, 366

[Especially if you're a big woman, you know] #111115, 367

[Uh, I have heard other women, uh, you know, maybe that's some of the reason as to why they don't have them, is because of the ...some of the discomfort] #17891, 137

[And there are some people, you know, that are just intolerant of certain things] #17891, 142

[I just hear other people say that when they get them done, they push them down too hard and stuff] #18389, 633

[That's too tight] #18389, 636

[they (MW: radiology tech) pat them down on their breast to hard or too firmly] #18389, 646

[Well, like I said, some...some of them can be pretty painful, but that's about the only problem I've had] #19293, 154

[The only thing I have heard of, um, the discomfort factor] #21478, 154

[because your breasts have to be pressed between, I don't know if they are two plates or what they are] #21478, 155

[but I've understood that (MW: breasts being pressed) kind of hurts a little bit] #21478, 157

[I could see if a woman was very sensitive in her breast area, when they have to squish it a little bit, it may be tender afterwards] #25862, 322

[It (MW: mammogram) was uncomfortable for me to do it on my left side because I'm paralyzed] #25862, 325

[What they did was the...the machine kind of presses down on your breast It does] #25862,.338

[And that...that's what was uncomfortable for me] #25862, 340

[And trying to hold...well having someone else hold my left hand up in the air and then having my breast squished sort of, [*inaudible*] say, you know, it was a little uncomfortable] #25862, 341

[And because of the paralysis on my left side, I'm more sensitive on the left side than I am on the right] #25862, 344

[And that's...that was uncomfortable for me] #25862, 347

[Only thing, they just put it tight on there sometimes] #28, 254

[It's just, to me, sometimes they have it too tight on there] #28, 268

[and it feels uncomfortable also. It feels uncomfortable] #4, 289

[and then they have a plastic screen or whatever that comes down and smashes your breast firmly in between, like a sandwich really tight] #4, 298

[and you're not used to sticking your breast into something like that and squeezing it] #4, 301

[It's that sandwiching effect] #4, 307

[and that's part of the reason why I don't have it done, because it's so, it's very discomforting. It's very discomforting.] #48, 421

[Um, it's a little..it's a little uncomfortable when they're doing it] #7, 296

[when I have a mammogram on that side, you really do have to grit down and bear it a little bit more because everything is ..everything is more sensitive.] #7, 305

[And it stays sore for a long time] #7, 308

[Tenderness for days later] #93, 432

[yes, you can't brush against yourself or activity, no sex, that's out (MW: from tenderness after mammogram)] #93, 432

[but just hurt] #93, 434

[it's very tender for a few days] #93, 434

[What did the machine do to me, from the trauma that it just gave me and believe me] #93, 437

[Okay, the machine's gotta do something, the machine does not know that the pain it's inflicting, it's just trying to get this asymmetric breast to contour like a pancake and it's just not happening, but it manages to flatten it out with such pain] #93, 440

[It's like closing your finger in a car door, how long do you want to keep your finger in a car door. And you're gonna take your second finger and put it in another car door? You know what you just went through.] #93, 445

(Field note: Interviewee is using finger slam in door as metaphor for mammogram)

[Or if that's the case, do them both (MW: breasts) at the same time, you got to have two machines, I'm sorry, get the pain over with. Okay?] #93, 450

[Some people are very afraid of going in the dentist chair because they know what's going to happen. The needle going into the gum, they know the pain is coming.] #93, 462

[And they (MW: dental staff) have the nerve to say 'relax, this won't hurt but a minute, just relax' (Field note: Interviewee is using dental appointment metaphor for mammogram)] #93, 465

[And you're standing there like this, relax, relax your shoulders, all this is tense, that's what I'm looking at when I walk into that room. And it's becoming more frightening, okay?] #93, 467

[Just the thought of going and having this (MW: mammogram) done, from the pain I have to endure when I don't feel it when I go in] #93, 476

[Well I'd just as soon almost wait until I feel like it's almost broken before I come have that painful test (MW: mammogram) because it hurts just as bad.] #93, 481

[And I'm on the verge of being on the other end of that catch 22 and not having another one (MW: mammogram) done for maybe another two or three years, just from the pain] #93, 500

[Psychologically I'm almost like this, give me a valium or give me a shot or something before I go in there (MW: for a mammogram) because I'm getting very frightened of that pain.] #93, 504

[It's like you're having a baby, you know, it hurts to have a baby #93, 507

and a bundle of joy comes out]
[but some women if you can just put it off, I'll wait another few years #93, 509
before I'm gonna have another baby because I know the pain's coming]
[and then some women it don't bother. Does that make sense, #93, 512
what I said? (Field note: I think client is referring to
the pain from having a baby)]
[this big machine and here I am, it's got my little breast, #93, 528
steady flattening it out like a little pancake]
[and I'm up like this, and they're saying relax, push in your #93, 531
shoulders out, calm down, relax]
[That's, that's frightening, okay, I'm not a masochist. I don't get #93, 533
any enjoyment out of it, (MW: mammogram) okay? Okay]
[You see it (MW:Mammogram) coming and you automatically tense up] #93, 556
[It's (MW: mammogram) as if you're watching a car accident in #93, 557
slow motion you see it, they're gonna collide]
[or a car is gonna impact with someone] #93, 559
[and there's nothing you can do] #93, 560
(Field note: Interviewee is using car accident as metaphor for mammogram)
[you stand there and you're on edge] #93, 560
[I see this machine and the lady takes her foot, she puts her #93, 561
foot like she's hitting the accelerator]
[and your breast and she's trying to bring the machine down to you, #93, 563
and if she hasn't come down to your height enough then she's
pinching the skin up underneath]
[and you just don't have it in there at a good fit] #93, 567
[and the machine is just too painful] #93, 568

Exposure to the X-Rays

[The only think I would think would be the exposure to the x-rays] #10943, 368
[I don't know that it's (MW: radiation) that much]
#10943, 369
[Any time I go to x-rays I just feel antsy about it] #10943, 370
[the x-rays and radiation] #10943, 372
[I don't know how high it (MW: radiation) is or anything]
#10943, 373
[but I've heard any stuff (MW: radiation) isn't really good]
#10943, 374
[Any of the radiation or whatever...what...what happens] #10943, 379
[Because, you know, you figure now, the person that's taking the #10943, 380
pictures, they jump behind a lead...[*laughs*] a lead shield]
[And I'm standing up there, getting the full...full impact (MW: radiation)] #10943, 382
[Yeah, right, where are you (MW: radiation technician) going?] #10943, 384
[I mean, I'm up here getting shot up with this (MW: radiation)] #10943, 384 [So
what, you (MW: Radiation tech) jump behind a lead]
#10943, 385
[I mean, that says something (MW: that radiation tech is #10943, 386
behind lead shield)]
[So I'm sure there...there are some dangers there (MW: radiation)]
#10943, 387
[and I told the doctor I don't want to keep it radiated because #111116, 909

even though we think it's nothing, what if it's something, blah, blah, blah]
[For example the time that I was in there, um, getting one, I was thinking, uh, okay, why they don't have a lead jacket or something over me so this, um, radiation wouldn't go to the rest of my body] #14988, 247
[I was thinking the rest of me should've been protected as opposed to just trying to make sure to get my breast over to get this mammogram] #14988, 254
[So, I felt like maybe if anything was going to happen, I would get something from this (MW:mammogram) as opposed to finding I don't have cancer] #14988, 257
[The only thing I can think of is the x-ray, you know] #25862, 377
[Maybe the x-rays might do something to someone's body adversely, as opposed to me, you know. I don't know.] #25862, 382
[Because you know it's like they have these x-ray] #4, 294

It Didn't Really Hurt

[but it didn't really hurt] #11, 170
[and it doesn't hurt that long if it does hurt]
[you know, it's only what ten seconds or whatever and they press on it and it's over] #11, 171
[so I think a lot of women and maybe the older women you know that were before the newer technology, they scare the other women coming up because it hurt them so much then] #11, 173
[but it doesn't hurt now] #11, 177
[to me it didn't hurt anyway] #11, 178
[It didn't hurt or anything] #12603, 290
[They put quite a bit a pressure but it didn't last long, so it wasn't a problem] #12603, 291
[Uh, because they down on the breasts, you may have some discomfort, but just as soon as that's over, it's gone] #17891, 135
[And maybe it's...maybe it's pain to them, but it's discomfort to me] #17891, 141
[It just needs to be firm, tight enough, but not to squeeze it, you know, to hurt] #18389, 657
[But it's a little uncomfortable but it's so temporary that you can deal with it 3 or 4 seconds that they tell you to hold your breath. Whatever.] #7, 299
[It's not bad] #7, 313
[It was just a little bit uncomfortable at the time, but it didn't last long] #25862, 330
[And when I go in there to have a mammogram, I've already set myself in a mindset anyways. That, you know, this is something that's going to be for a few minutes, then get through with this and go to the next] #17891, 144

No Problems

[I've had mammograms and I haven't had any problems with them] #111112, 303
[I've been blessed that, uh, the tests that I've had always have come back everything's okay] #111112, 304
[And uh, I can't see any problems with mammograms] #111112, 306
[I have no problems] #111114, 277
[but I don't -. No problems][*laughs*] #111114, 277
[Um, I don't think it's a problem] #111115, 357
[You know what, honestly, I don't think there are any] #111116, 902
[They say there's very little risk] #111116, 903

[None that I remember of] #125(mp), 201
[Problems? I don't have no problems] #12603, 290
[I don't have a problem. Not that I know of] #12603, 293,297
[What problems? I don't know. I don't know] #13657, 288
[None, there's no problems][*giggles*] #14, 405
[No problems] #14, 405
[No problems] #14, 406
[So, I don't know if there's anything...if mammogram has done anything. I haven't heard about it.] #14988, 260
[None, none that I know of. None.] #15556, 600
[Nothing really] #15868, 490
[Nothing] #15868, 501
[None] #16553, 198
[Me personally, I have not had any problems, uh, during the exam] #17891, 134
[Nothing for me] #18389, 633
[Other than that (MW: hurts), I don't know of any (MW: problems)] #21478, 158
[I haven't really heard of any women having any kind of adverse reactions from having a mammogram] #25862, 384
[I never have] #25862, 386
[None] #28, 254
[It's no problem at all] #28, 255
[No problem at all] #28, 268
[but other than (MW: the cold) that there's no problems] #30903, 348
[No problems] #400042, 91

Mammograms Are Helpful

[Yes you do (MW: have a mammogram), you know, and that's weird] #11, 182
[I think it's very helpful to have that (MW: mammogram) done] #111112, 313
[But as far as myself, I...I think it's...I think it's (MW: mammogram) very, very, very efficient] #111112, 311
[I just feel better] #111114, 277
[So they said to get a good x-ray. That's about it.] #28, 270
[but make sure that you don't have cancer] #400042, 91
[And, uh, depending on how evasive the surgery was, um, um, you know. So, you kind of...you kind of like oh, do I have to go through that (MW: mammogram) again, you know. But you do] #7, 309

I Don't Know

My understanding from my friends] #109,168
[I haven't had a mammogram] #109, 176
[I don't know if people with other illness, say like pacemakers and that type of thing, if it'll affect them through the radiology type of thing. I can't say...I really can't say] #111112, 307
[I don't know, girl] #111113, 213
[I can't even tell you because I don't know] #111113, 213
So I...I don't know] #111113, 217
[Well, I don't know if there are any (MW: problems from mammogram)] #25862, 377

It is Cold

[No, it's just cold] #14, 406
[the actual machine or plate or whatever it is, is cold] #30903, 347
[I remember something being cold, that thing that you press against, you know] #30903, 361
[and its sometimes cold, you know, it's not warm, you know] #4, 308

One of Those Psychological Things: That Fear

[but um I think we have a you know a habit of doing that, you know, it's like oh no you don't want to get that (MW: mammogram) done] #11, 180
[I know when they were following, um...because I had my breast bump followed] #111116, 903
[And then I reached the point where I didn't even want another mammogram] #111116, 907
[it was one of those psychological things] #111116, 914
[Um, that fear] #111116, 919
[so- Um, that I could be a candidate] #111116, 929
[I mean, because we have so many other kinds of cancers [*tape skips*]-] #111116, 929
[Okay, I had had this thought, you know they say that, you know, you're high risk if it's your mother's sister] #111116, 931
[but you know what, it (MW: breast cancer had to be somewhere for that one whose mother and sister are not] #111116, 934
[but the lady who breast fed all five of her children, all of a sudden here she is, the breast cancer had to come from somewhere] #111116, 935
[so- And we have this saying [*inaudible*] that's what I want to say right now, it's like not me God] #111116, 938
[I think the only that you would like say they did find something] #15868, 490
[then they had to let you know that you need probably to come in for another one (MW: mammogram)] #15868, 491
[that would scare me if they tell me that I need to come in for another one (MW: mammogram)] #15868, 493
[Just the results can cause, cause um, cause you to worry again] #15868, 501
[for instance say somebody a woman has felt some type of lump or something and then she had the mammogram and then she's worried if they found it and you know if it's cancerous or whatever] #15868, 503
[And then I think if they do find it (MW: lump)] #15868, 507
[and they call you that there's some question and you have to go back in] #15868, 508
[I think it will cause a lot of stress on a person, by you know by that (MW: go back to doctor re: question on mammogram)] #15868, 509
[A guess positive, I don't know what they call it, a positive something, a positive report from your, from your mammogram as opposed to a negative] #15868, 511
[Might have something you know that there's positive. Positive in a bad way] #15868,520
[Fear. Fear.] #4, 284
[Fear. That's it. That's it. Fear. That's for me, it's fear] #4, 288
[And hopefully they (MW: radiology tech) did a good job] #4, 312
[and they (MW: radiology technician) don't find anything] #4, 313
[and you can come back next year (MW: for next mammogram)] #4, 314
[Fear again. Start the process over (MW: with next mammogram)] #4, 318
[Especially if the technician, uh, does not have her technique down #7, 297

and...and whatever. We all know that.]
[I don't know what it (MW: mammogram) really did besides kind of, #44, 118
that was kind of, that was quite an interesting little scary kind of little time to go through]
[and it (MW: mammogram) was around Christmas time and it's #44, 122
like I thought in the back of my mind like what is my, how is, how is my holiday gonna be if they say I do or what, you know, or just what's gonna happen]
[I guess the fear of going in there and taking the mammogram, it's just like a, #44, 126
just a fear, brings fear on you]
[Of the results (MW: the fear)] #44, 1
[The fear is really getting worse] #93, 522

Mammograms are Time Consuming & Difficult

[And I...I don't know, that was just my thought when I was in #14988, 251
there getting it (MW: mammogram) because it was so difficult]
[and so time consuming to get it (MW:mammogram)]
[You just gotta take the time to do them] #30903, 349
[Take the time, you know #30903, 355
go to the appointment, and you know …]

I Am Not A Good Example

[and like I said, my breasts are way different than normal people] #11, 178
[I am not a good example] #111113, 215
[because I...I'm the...I'm the example you would show like,
you don't want to be this person]

You Got A Mouth. Use It.

[But like I said, you got a mouth. Use it.] #18389, 635
(Field Note: Interviewee is saying "speak up if it hurts")
[And it's all...no I don't, you know, you don't do it like that. #18389, 650
I want it done like this, and I just explained it and just tell
(MW: radiology tech) them.]
[And if they (MW: radiology tech) don't like it, too bad. I don't care]
#18389, 653
[And I just ask why do you have to put it that tight] #28, 269

Barbaric Ages/Old Technology

[and going through that screen thing...that machine] #111115, 365
[And I have, uh, is it...it's like I watch people (MW: radiology tech) #18389, 636
and that when...I know that they're doing it on purpose or they're doing it just to be mean]
[And so, I went back and they (MW: Radiology tech) want to #18389, 639,646
to try to be mean..when they mash into, uh,]
[They (MW: radiology tech) have to...it shouldn't be that #18389, 648
tight so it could hurt]
[I mean, tight enough so that it'll stay in place, but not tight enough to hurt] #18389, 649
[But, if you're talking about me, and you're (MW:Radiology tech) #18939, 654
putting pressure on it ...unnecessary pressure, you don't need all that.]
[Oh my goodness. You know, it's so, it seems with all the modern #48, 401
technology that have progressed over the years, they can not find a
better machine to do these mammograms for women]

[They find all this modern technology to do exams for men, you know] #48, 404
[but we're still in the barbaric ages when it comes to doing high tech technology for women, you know] #48, 406
[and there has to be some kind of device that somebody can come up with where you don't have to stand on your tippytoes and get smashed] #48, 408
[So somebody in the medical community, whether it be a woman because there's a lot of women in the medical community now] #48, 411
[that will have the guts to stand up and say no, you know, you guys are doing all this research for men] #48, 413
[men are you know are being given the health benefits more so than we are] #48, 415
[so why do we have to keep going through the barbaric ages and having this old technology?] #48, 417
[Why isn't there new technology and better technology to detect breast cancer than being smashed on each side, you know] #48, 418
[And I must say that, though, after having breast cancer and going through, uh, what they do to your breast] #7, 302
[and then you wonder all that mashing] #93, 435
[what did they do, they're squishing things out of context] #93, 435
[Is there any swelling? (MW: from mammogram)] #93, 437
[and they take you in the room and tell you take your gown off] #93, 522
[and you're looking at this big computer machine,] #93, 524
[what if it (MW: the mammogram machine) goes on the rampage and gets stuck] #93, 525
[I mean hey something happens to the, something happens to the machine where they can't release all this pressure] #93, 526
[It's wrong, very wrong to subject us to this (MW: mammogram)] #93, 569
[They would never, a man would never put his penis in a machine] #93, 570
[a man wouldn't put his penis in a machine like this and squish it] #93, 571
[And a man made that machine too] #93, 573

How Can You Fix Something That's Not Broken?

[If something is not broken, how can you fix something that's not broken, but you don't know until you initially get this painful test (MW: mammogram)] #93, 478
[Well, what can I say? How can I tell you? When I feel like my breasts are okay, so why torture myself in going to see if I'm okay] #93, 489
[when I've taken the initial steps of palpating, of touching myself, and I feel I'm in no distress, there's no leakage, no drainage from the nipple, why go to the doctor? Why go have that test? (MW: mammogram)] #93, 492
[This is what I mean, why try and fix something if it's not broken?] #93, 496
[I feel like it's okay, but then again by the time I initially feel something then I would have waited a little too long. It's a catch 22.] #93, 497

You Want To Participate Well

[But they have to squeeze for some reason to get a good picture] #4, 302
[so you want to you know participate well because you don't want to make a mistake and you have to do it (MW: mammogram) again. You know?] #4, 309
[and so you want to make sure (MW; to participate well in mammogram)] #4, 309
[I know you don't want to have the deodorant and perfume or nothing, #4, 309

you want to be clean so that you just get it over]

Not Grouped

[I don't remember for how long, it was on six month follow-ups] #111116, 905
[So then they did ultrasound which they had started doing anyway] #111116, 912
[I don't, to my knowledge...I mean, my mother and my sisters and no aunt or cousins have had breast cancer that I'm aware of on my mother's side] #111116, 919
[My father's side, they're so tight-lipped, we would never know] #111116, 922
[and I mean all my dad's sister's would've lied] #111116, 924
[I really don't know of any, but if I had to think about it] (Field note: statement appears to be said while thinking of a response) #14988, 246
[But the nurses were real nice and they assisted me when I had to hold my arm up straight over my head. I couldn't do that, so one of them held it and I...they were able to fit me into the machine] #25862, 326
[That was the result from the ruptured aneurysm I had in my brain, right side. It bled on the motor system for my left side. I can still feel, but I cannot...I don't have that fine motor dexterity and I don't have my elbow function or anything like that. This like this, but I can do my elbow and my arm, you know, up and down like this. But that's all that it does. So I'm not able to do that. And the same as with my hip, moves my leg for me.] (Field Note: This is an aside on her health problems; I left it together) #25862, 353
[Oh, it's when they're taking the mammogram. You know, when they let it down and they tell me -] #28, 259
[like this machine,like two plastic things] #4, 295
[and you have to take and put your breast on this like little tray or whatever] #4, 296
[Well totally they say to look at your breasts on the inside] #44, 117
[that, I think I went through it (MW: mammogram)two years ago] #44, 121
[have you had one done?](Field note: Interviewee is asking interviewer if she has had a mammogram) #93, 439
[You said be honest, its just the way it's coming out, I'm sorry] #93, 535
(Field Note: Interviewee is talking to the interviewer . . . apologizes more than once for openly articulating her feelings)
[You can't sugar coat life.] #93, 540
[I tell my family that, I'm sorry it comes out this way, but you can not sugar coat life and this is it in black and white.] #93, 544
[I'm sorry] #93, 573

Appendix: Example of Coding Worksheets for Worst Fear

I would die (#109, 188)

Dying (#10943, 397)
Dying (#11, 189)
next thing you know they're gone (#11, 206)
Dying and leaving my family (#111112, 326)
I was going to die (#11114, 300)
Dying (#14, 415)
Dying (#16553, 207)
it will take my life and take me from my family (#17976, 146)
How long am I going to be here (#18389, 668)
you're cutting into my time and I ain't read to go yet (#18389, 672)
it cuts your life short, and that's it (#18389, 679)
Dying...that I would probably not live as long as I'd like to live (#21478, 111)
To leave this space, this plant, without having really done what I wanted to do (#21478, 408)
not surviving (#48, 432)
so to say that I don't fear death would....is not a lie, but to say that I'm ready to go, I have to say I'm not ready to go (#7, 329)
It's just the death, um, I'd probably withdraw more into myself (#93, 601)
Death, it's the final, it's a death sentence (#93, 646)

Telling me I have cancer (#111115, 377)

Just be knowing it (#125rw, 282)
Just to know that I had breast cancer...just the thought of it (#125rw, 286, 290)
I just don't want to ever be really sick or diagnosed with cancer (#125rw, 304)
I don't know...the worst would be if he [doctor] tell me I have cancer (#12603, 322)
That would be the worst thing, if I was diagnosed with it (#14988, 267)
is the mammogram something that will or won't cause me to have some kind of operation or something, surgery or whatever (#15868, 547)
the worst thing is that it's cancerous, you know (#15868, 557)
If it's malignant, I'll be thinking about dying, if it's benign, I would be thinking about surviving (#16553, 220)
You say this is what's wrong with my body, does it, do I look any different (#93, 610)

It was too late to fix (#109, 187)

you're never really sure how fast it's gonna progress (#11, 201)
That it [cancer] would be so far-gone, they would tell me I only have a short time to live (#111113,222-223)
That's about the worst thing for me. The fact that, it would be so far-gone that I couldn't do anything but pray to God (#111113,271)
them not detecting it in time (#17976, 144)
that it was in the probably the last stages of it where there was no prevention or anything to stop the breast cancer (#44, 143)
if I was a stage 4 and no matter what they did....that it was iffy (#7, 322)

your mortality hit you right in your face again (#7, 323)
to find out if it was curable and to give it the fight of my life (#7, 333)
what's the depth of the current infection? (#93, 586)

Languishing (#109, 190)

I think the long suffering would be, um, the worst (#10943, 401-402)
The long suffering (#10943, 442)

Having to go through chemotherapy (#10943, 403)

Can't imagine the pain (#10943, 448)

your cells are just going crazy inside your body and I can't imagine what that pain feels like (#10943, 451)
to feel that all over or in one particular spot and it never quits (#10943, 458)
it would be close to driving you crazy (#10943, 459)
Excruciating pain (#111112,332)
Pain. I'm not good with pain. Pain and fear (#4, 323)

Not being able to move around (#10943, 461)

Not being able to go outside when I wanted to (#10943, 462)
being able to not do things that I used to do (#648)

Getting Right Treatment

if I had to get chemo or radiation, that it would treat me well because it can make you sick (#14, 422)
That I get the right kind of medical treatment (#14, 436)
I would like the treatments, if I had to have it, not make me sick. I'm hoping that researchers can treat this cancer a little bit better and it's not that bad anymore (#14, 459)
not being treated or not be a cure, or to where I would not be able to go into remission (#17891, 154)

Dying before I got old enough to see my grandchildren (#11, 189-190)

But to know that I would not be here to see my children grow up, my grandchildren...to know that I would pass before my parents would be devastating to me (#111113, 230)
I wouldn't get to see my kids and my grandchildren (#111114, 301-302)
I wanted to help my kids grow up...my grandkids (#18389, 674)
But the worst thing I would think about is my granddaughter I have. Who's going to take care of her? (#28, 281-283)

My [family's] concerns would be so hard (#109, 194)

It would be so painful for them. Their concerns would be so hard for them, not for me 9#109, 193-195)
Have to have my family to take care of me like an infant because I couldn't take care of myself (#111112, 331)
drain my family emotionally (#25862, 399)

Affect my daughters (#125mp, 208)

Maybe this is something that might affect my daughters (#125mp, 208)
worry that they'd [daughters] be struck with it and how they'd be able to hand and deal with it (#125mp, 220)

Knowing where the cancer is (#111115, 379)
Tell me they are going to cut my boob off. I would have a tissy, probably have a heart attack right there.(#111115, 404)
Don't do this to me, don't take my breast, that scares me (#111115, 407)
Knowing it's [breast] gone and you can't replace it (#111115, 413)
we're going to have to take your breast, I just couldn't deal with it (#111115, 417)
later they could come back and say we got to take the other one. Then I'd be breastless (#111115, 421)
I think having a mastectomy and trying to deal with that would be worse than dying (#111116, 954)
but there's something about, I think maybe because it's part of a woman's body and then to have some type of surgery to remove it (#4, 330)
Do you deem it necessary, doctor, for me to have it cut off right away? (#93, 589)

Losing my husband (#111116, 966)

If I had to get a mastectomy, that would mean that I would never get married (#111116, 979)
say it was like the last stage where you had to have your breast removed (#44, 147)
Now, if I had been one that had to have a mastectomy, I think I would just be devastated because that was my last resort...I only had a lumpectomy (#7, 353-356)

I don't know (#12603, 304)

I don't know how I would feel it I were diagnosed with cancer. I don't know what would be the worst thing. I haven't the slightest idea how I would take that (#12603, 318)
I don't know. I guess I wouldn't know that 'till it happened (#13657, 307)
I wouldn't know what to do (#400042, 97)
I just have to take one day at a time (#400042, 98)

Nothing (#15556, 606)

Nothing. I just figure if that's the Lord's will, maybe he's trying to teach me something (#15556, 608)

I don't say bring it on, but I...I don't fear...I don't fear it (#7, 363)

I wouldn't want anyone to pity me (#111113, 261)

I would just do what I had to do and go on, I mean, you can't sit and feel bad... sit on your pity-pot and shy why me, poor me (#111114,288)

I would have no one to blame but myself (#111113,273)

I would have no one to blame but myself because I have never been checked (#111113,273)
So that would probably eat me up – the fact ...I'd be like well you should've been in there earlier (#111113, 275)
I probably would blame my self a whole lot (#111113,287)
Pray to the Lord to give me the wisdom to forgive myself for not getting in sooner (#111113, 288)
What did I do to deserve this? What did I do wrong in my life? (#93, 603-605)
Well if it doesn't run in my family and I were diagnosed with it, what did I do, or what did I not do to get this? I have no answer even for myself but these would be deep questions that I would feel (#93, 633)

That I would probably stress out for a minute (#15868, 527)

anybody probably would stress out and you know like freak out inside...what am I gonna do (#15868, 536)
am I gonna lose it and have to lock me up somewhere or am I gonna just go on? (#15868, 539
freak out, go off the deep end for a minute (#15868, 567)

Fear, in itself, can hurt you and kill you (#111113,282)

There was really no reason why you didn't go...and this could've been detected but you just was so afraid to see a doctor and find out what was really going on (#11113, 277)

fear, in itself, can hurt you and kill you because it can let you sit back on it so long (#111113, 283)

There are things that can be done if you take the initiative to get off your behind and go get checked...those who sit back, miss out (#111113,296)

Not being able to reach out in faith for healing (#30903, 367)

There isn't a guaranteed cure (#19293, 163)
I would be afraid, of course, because I know there's no cure for cancer, really, even if you catch it in time. There isn't a guaranteed cure (#19293, 161-164)

TAKING CARE OF YOURSELF: **A Study of Factors Influencing African American Women's Participation in Breast Cancer Screening**

Feb. 21, 2002 Interim Report of Open Codes

Question 1: **When you think about taking care of yourself as a woman, what do think about?**

Checking Out What's Going On Interior
Letting Me Know if Anything's Growing in There

Trying to Take Care of Myself

Taking Time Out

Nurturing Myself

Taking Care of Family Is Making Me OK, Too

Needing to Take Better Care of Myself

Wanting to Be Around

Thinking about Health Issues

Thinking about the Way My Body Changes

My Whole Being

Going to Doctor's Appointments

Holding Back Going to Doctor's Appointments

Mammograms Are Important

Mammograms Are Not Necessarily Safe or Effective

Being Embarrassed to Disrobe for a Doctor

Not Thinking about Taking Care of Myself as a Woman